



Long Term Care Coordinating Council
Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Full Group Meeting

8:30 – 10:00

Thursday, June 6, 2013

Child and Family (formerly Casey Family Services)

Downstairs Gathering Space

1268 Eddy Street

Providence, RI 02903

MINUTES

I. Call to Order

- a. Lt. Governor Roberts called the meeting to order at 8:30 a.m.

II. Presentation of the Draft State Plan with an Overview of Each Section

a. Introduction and Process Steps

- i. **Slide 1 + 2** Lt. Governor presented on the formation of the subgroups and their roles in the full workgroup. She explained that there were listening sessions held throughout the state to ensure that the state plan is responsive to the needs of people who live with Alzheimer's Disease and their families.
- ii. **Slide 3** Director Taylor discussed the drafting process of the state plan and explained the extensive process of review and public comment that the state plan underwent. The formal presentation of the State Plan for Alzheimer's Disease and Related Disorders would be at the Alzheimer's Association Caregivers Conference on June 25th.
- b. **Caregivers** – Kathy McKeon presented on the recommendations that were of priority for the Caregivers subgroup. There was much discussion about the necessity of new resources and connecting resources to ensure that caregivers are properly trained to deal with issues that arise from caring for someone living with Alzheimer's Disease and related disorders. Additionally, the recommendations encouraged peer mentorships and workplace supports to prevent caregiver burnout.
- c. **Access** – Lindsay McAllister presented on the recommendations from the Access Subgroup. Many of the recommendations are the bridging of resources that already exist in

Rhode Island. There is an emphasis on using expertise from the POINT offices to guide families.

- d. **Legal** – Tom Enright presented on the recommendations from the Legal Subgroup. There are many areas of elder law that need to be addressed. The legal areas of elder driving, financial protection, and guardianship are important to ensuring legal justice for people living with Alzheimer’s Disease and related disorders.
- e. **Workforce** – Gail Patry presented on the recommendations from the Workforce Subgroup. The central theme of the workforce subgroup was the emphasis on workforce development through training and education. This meant that there could be a potential for standardizing and unifying the curricula of caregivers. Like the recommendations of the caregiver subgroup, some of the recommendations for the workforce outline the need for training modules for caregivers to access in order to learn the basics of caregiving.
- f. **Long Term Care** – Kathleen Kelly & Rick Gamache presented on the recommendations of the Long-Term Care Workforce. They discussed the need to improve quality across settings. Much of the quality of care issues arise from care transitions as well as cultural competency issues. Some of the recommendations included issues related to support services because the recommendations note that the quality of long-term care is not often about the actual medical treatment of the people living with Alzheimer’s, but their comfort level in certain settings and the levels of support that they receive.
- g. **Research** – Peter Snyder presented on the recommendations of the Research Subgroup. There was an emphasis on the necessity of disseminating research findings to improve care. The expanded field of Alzheimer’s research has improved the knowledge of the disease; Snyder notes the importance of enrolling people with Alzheimer’s to participate in clinical trials in order to advance knowledge.

III. Administrative Items

- a. Approval of Minutes from April 4, 2013 Meeting.
- b. Lt. Governor Roberts noted that she and Catherine Taylor would be getting the word out for the state plan this summer. Additionally, there will be a public comment period and she encourages everyone to get out the word so that the public can comment and better inform the plan so that it reflects accurately the lived experiences of people with Alzheimer’s and related disorders.

IV. Public Comment

V. Adjourn